

‘It makes the patient’s spirit weaker’: tuberculosis stigma and gender interaction in Dar es Salaam, Tanzania

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SUMMARY

SETTING: Dar es Salaam, Tanzania.

OBJECTIVES: To describe tuberculosis (TB) related stigma and to understand how it interacts with gender to affect access to care.

DESIGN: Eight focus group discussions were held among 48 TB patients and their household members, and a thematic content analysis was carried out.

RESULTS: The main components of stigma were fear, self-isolation, ostracization, loss of status in the community, and discrimination by providers. Participants described the cultural context in which stigma operated as characterized by a general lack of health knowledge, cultural beliefs about TB, and engendered beliefs about disease in general. Both genders described some similar effects of stigma, including relationship difficulties and

specifically challenges forming new relationships, but many effects of stigma were distinct by gender: women described challenges including assumptions about promiscuity and infidelity, as well as rejection by partners, while men described survival challenges. Stigma acted as a barrier to care through a cyclical pattern of stigma and fear, leading to health-seeking delays, with resulting continued transmission and poor health outcomes that further reinforced stigma.

CONCLUSION: TB-related stigma is prevalent in this setting and operates differently for men and women. Interventions designed to increase case detection must address stigma and its interaction with gender.

KEY WORDS: barriers to care; focus groups; qualitative research; case detection; thematic content analysis

DESPITE HAVING A KNOWN cause and treatment, tuberculosis (TB) remains a major cause of morbidity and mortality worldwide. In 2015, an estimated 10.4 million people fell ill with TB and 1.4 million people died from the disease, making it the leading killer due to an infectious disease worldwide.¹ Approximately 4 million of those incident cases were not diagnosed or reported, meaning they likely did not receive appropriate treatment. This huge number of missing cases leads to increased morbidity and mortality and helps drive the TB epidemic through continued transmission within communities.

Many factors contribute to low TB case detection in high-burden settings, including economic, geographic, sociocultural and health system barriers.^{2,3} Primary among sociocultural barriers is TB-related stigma. There are several definitions of stigma, but for the purposes of this study we use Goffman’s widely used definition of stigma as ‘an attribute that is deeply discrediting’ and that transforms the person it is inflicted upon ‘from a whole and usual person to a tainted, discounted one.’^{4,5}

The World Health Organization (WHO) defines gender as ‘the socially constructed characteristics of women and men—such as norms, roles and relationships of and between groups of women and men’,⁶ in contrast to the purely biological attributes of an individual’s sex. As such, gender often interacts with other social constructs, such as stigma. The literature on TB-related stigma demonstrates that it can act as a significant obstacle to accessing care,^{7–9} and often emphasizes its effects on women more significantly than men in high-burden countries,^{10–16} including in the health care setting.¹⁷ However, prevalence surveys and other epidemiologic data consistently show that TB prevalence is higher among men,^{15,18,19} and that men may be less likely or able to access care than women in many settings.²⁰ Furthermore, comparison of past surveys shows that the disparity in TB prevalence between men and women has increased over time in some parts of the world. Taken together, these findings suggest a complex relationship between TB stigma, gender, and access to care that TB programs need to address and be sensitive to in order

Table Description of focus group participants, including gender and TB status

	Women	Men
TB patients	2 focus groups of 6 members each	2 focus groups of 6 members each
Household members of TB patients	2 focus groups of 6 members each	2 focus groups of 6 members each

TB = tuberculosis.

to serve their patient populations effectively and equitably.

In the light of these factors, we sought to understand TB-related stigma and its interaction with gender in Dar es Salaam, Tanzania, a high TB prevalence country with a much higher prevalence-to-notification ratio in men than women,²⁰ and an estimated treatment coverage gap of 63% overall.¹ The goal of this study was to characterize the current state of TB-related stigma in an urban East African setting, to understand how it operates as a barrier to care seeking, and how it differs by gender, to inform the development of interventions to reduce barriers to care and increase case detection in this and similar settings.

METHODS

Study setting, recruitment, participants

The study was conducted in the Kinondoni District of Dar es Salaam, one of three districts that make up the city. Kinondoni District is an urban district with a population of just over 1 million, including many urban migrants. Participants were purposively sampled from a parent TB contact investigation study being conducted at five primary care clinics in Kinondoni District at the time, for which consecutive patients diagnosed with TB were recruited and enrolled from four government-run health clinics and one private clinic. For the present study, we recruited and enrolled subjects from two distinct populations, 1) patients recently diagnosed and being treated for TB, and 2) their household members, to understand how stigma is perceived both by patients recently diagnosed with TB, and by individuals not currently diagnosed but at a high risk of developing the disease in the future.

All participants provided written informed consent. The institutional review boards for Muhimbili Medical Research Centre, National Institute for Medical Research, Dar es Salaam, and for the University of California, San Francisco, CA, USA, approved this study.

Study procedures

A discussion guide for the focus groups was developed, informed by the WHO publication 'Addressing TB in poverty control'² and by measures of health-related stigma.^{21,22} Focus group discussions (FGDs) were conducted with enrolled participants and were designed to elicit an understanding of

participants' beliefs and experiences regarding TB-related stigma. The guide included prompts for information from participants on their understanding of TB, including its cause and transmission mechanisms, their community's beliefs and feelings toward people diagnosed with TB, and their personal experiences with TB-related stigma. All FGDs were facilitated by a local sociologist and conducted in Swahili, the local language. FGDs were audio-recorded, transcribed, and translated into English. FGDs were stratified by gender and by patient/household member status to elicit the unique perspectives of each group (Table).

Data analysis

Thematic framework analysis was used to analyze the FGD results.^{14,23} After an initial review of the transcripts, a thematic framework was developed to organize the data according to the major themes that emerged. Using this framework, two authors (CM and JH) then independently reviewed and indexed FGD transcripts, identifying each relevant passage and labeling it with the appropriate code. The authors together resolved any differences in coding. Some passages were assigned more than one code. The passages and their codes were then charted into a spreadsheet for further exploration and analysis into each thematic area across all focus groups. The findings of the analysis are presented below, along with sampled quotations.

RESULTS

In July 2013, we held eight FGDs of six participants each, four groups with TB patients and four with their household members, comprising a total of 48 participants. Participants described the key components that make up TB-related stigma, the cultural context in which stigma is expressed, and the effects of stigma. The Figure displays a conceptual framework of TB-related stigma as described in the present study, including the relationship between gender and stigma as described by the participants.

Components of TB-related stigma

The main elements of TB-related stigma to emerge from the FGDs were fear, self-isolation, ostracization and loss of status in the community, provider discrimination, and the changing face of stigma.

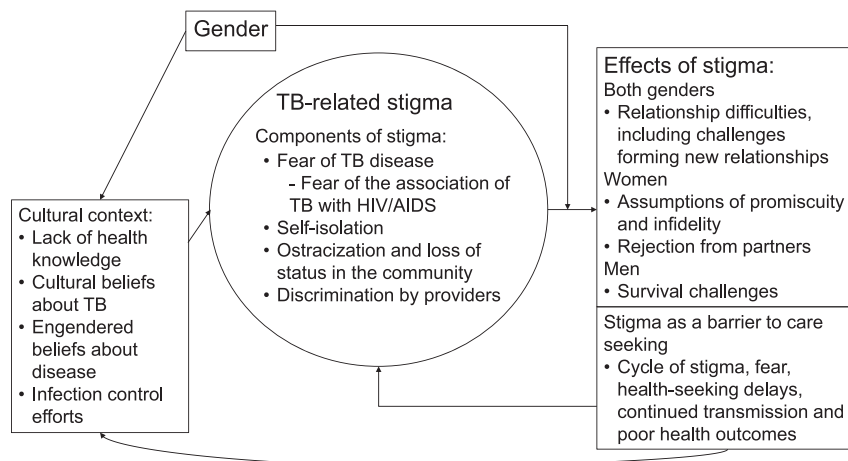


Figure Conceptual framework of TB-related stigma as described in the study, including its primary components, the cultural context in which it operates, and its effects, as well as the interaction between gender and stigma. TB = tuberculosis; HIV/AIDS = human immunodeficiency virus/acquired immune-deficiency syndrome.

Fear

Participants often reported feelings of fear related to TB.

I used to perceive it as a very horrifying and scary disease. (Female patient)

I was scared of people with tuberculosis... (Female patient)

He is just worried; he is scared even to go to the hospital for medication... (Female household member)

Participants mentioned that a large part of the fear of TB was due to the close relationship of TB with human immunodeficiency virus/acquired immune-deficiency syndrome (HIV/AIDS). In 2013, an estimated 37% of incident TB cases in Tanzania were co-infected with HIV.²⁴ Respondents often reported that a TB diagnosis in their community was perceived as equivalent to a diagnosis of HIV/AIDS, which was also equivalent to a death sentence:

Many fear that once diagnosed with TB, they will also be diagnosed with HIV/AIDS. That's why they don't go for the checkup till it's too late. So when people know that someone has TB, they say it's not TB alone, it must co-exist with HIV/AIDS. (Female household member)

... we could not differentiate TB from HIV/AIDS, so patient with TB were perceived as living-dead. (Male patient)

Self-isolation

Negative associations with TB often led sufferers to isolate themselves from their families and communities.

... it is a disease that once you get [it], you automatically isolate yourself from the community, you become an outcast. (Female patient)

I isolated myself from my family before they started isolating me, I feared if I disclose my status to them, they will ask me how I got TB and I could not answer. (Female patient)

... he starts worrying 'Oh! Everyone knows that now I have TB,' so he isolates himself thus he is stigmatized by his own instinct. (Female household member)

Ostracization and loss of status in the community

Such negative associations also often led to loss of status in the community and ostracization and neglect of the TB patient by the community at large.

Once someone has TB, his or her dignity in society automatically goes down; that person cannot be elected as a leader... (Male patient)

When I was diagnosed with TB, I started medications and I was very free to interact with others but they were not comfortable with me. (Male patient)

The community does not treat TB patients well... (Male patient)

Provider discrimination

Participants also described how TB-related stigma is sometimes expressed by health providers towards patients, further discouraging care seeking among those who are ill.

...at the health center...they handle TB patients as second class, it's like one is being stigmatized at the health center. (Female household member)

...it's true some of the health attendants use abusive language to patients. (Male patient)

Changing face of stigma

When respondents spoke about TB-related stigma, they often reported a reduction in stigma today compared with the past in their community.

They regard TB as a normal disease, they take good care of me, and they don't stigmatize me compared to the past days. (Female patient)

...nowadays I see changes... (Female household member)

Cultural context of stigma

FGD participants described several relevant factors in the larger cultural context in which TB stigma is expressed and experienced.

Lack of health knowledge

Participants described a lack of health-related knowledge and how it related to health-seeking behavior:

I could hardly know how a TB patient looks like until when I suffered from TB. In our community, knowledge about TB was so scarce that it was not easy to know anything about TB unless you have been diagnosed and counseled at the hospital. (Male patient)

... to some patients it can be a challenge, if they don't know where to go once they suspect TB and yet they don't have the courage to ask anyone for help, such patients will end up hiding their disease until the condition is life threatening or they may die. (Male patient)

Cultural beliefs about TB

Participants reported cultural beliefs about TB and how it is acquired or treated, including TB being sexually transmitted, inherited, cured by animals, or caused by curses or witchcraft:

I thought TB goes in hand with HIV/AIDS and the two are more or less the same in the transmission mode, that is, through sexual intercourse. (Male patient)

I knew TB is an inherited disease that runs in the family. (Female patient)

... we used to believe that the disease's source is from animals, so staying with animals for a considerable period of time would take the disease out of human body back to animals. (Male patient)

I knew TB was a disease that falls on the cursed or bewitched and without a cure, and worse... when I

got infected with the disease, I thought I was bewitched. (Female patient)

Traditional beliefs about TB often encouraged people to seek care with traditional healers:

... your relatives, instead of taking you to the hospital for further checkup, they believe straight away that you have been bewitched and you need traditional healers. (Male patient)

... they used to stay at home and go to traditional healers. When they became very sick, they started moving from one healer to another... (Female household member)

If you advise someone to go to the hospital, they say 'Aah...' but in reality? They go to traditional healers. (Female household member)

Engendered beliefs about disease

Participants reported cultural beliefs about disease as a female phenomenon:

Women are the main sufferers of the disease compared to men, I can't tell why exactly... (Female household member)

...most men do take diseases as something which belong to women. (Female patient)

... he will only think that she is sick because she is a woman. (Female patient)

Infection control

Some participants also described infection control efforts from family and community members in contact with a person with TB:

In my community some members do not talk or eat together with TB patients as they fear they will also contract TB. (Male patient)

...generally some people in my community, refuse to visit families with TB patients, they are afraid of getting TB infection. (Male patient)

Effects of stigma

Both genders

Both genders described the potential conflicts that TB-related stigma could cause in personal relationships, in particular maintaining current and forming new partner relationships.

I have witnessed several cases of family instability and domestic conflicts due to TB disease. (Male patient)

Frankly speaking, people rarely start romantic affairs with TB patients, and they think it is useless

to marry a TB patient even if a patient is on medication. (Male patient)

... it is hard for a man to get a girl when you are infected with TB. (Female patient)

Even men they can't agree to start any relations with unhealthy women. (Male household member)

This stigma is often extended to the person's entire family:

...if a family had a person with TB, people were strictly prohibited to marry into that family. (Female patient)

Women

Female participants in the study said that in their community, women diagnosed with TB were subject to judgment on their characters due to the belief that TB was a sexually transmitted disease and was therefore related to promiscuity:

...my sister had TB; my mother thought it was a sexually transmitted disease; she regarded my sister as a prostitute and stigmatized her. (Female household member)

Most men believe TB is a sexually transmitted disease like HIV/AIDS, and if their partner gets infected, they tend to divorce them. (Female patient)

Female participants also described specific difficulties in partner relationships that women often experienced due to being diagnosed with TB, including rejection by their partners due to lack of sexual activity:

Most of the women, when diagnosed with TB, they hesitate to disclose their [TB] status to their husbands... In that situation a divorce is inevitable. (Female household member)

... when you break the news and disclose to him that you have TB, most of them tend to find other women and leave their wives to finish their doses first. In most cases, men have no support for their wives. (Female household member)

Your husband can stigmatize you when he doesn't get sex ... and in the long run, the husband runs away and even divorces you as you will be a burden to him. (Female household member)

Other stigma comes as a [result] of the woman not giving her husband's right of sexual intercourse....Men get disappointed and they will start treating you badly like not leaving money for the upkeep of the family, getting other women, and coming back home late, giving all sorts of insults

like 'you are not woman enough.' (Female household member)

Men

Participants described that the effect of TB-related stigma on men was more directly related to their ability to maintain their daily activities required for survival.

What I know is that, once a woman discloses her TB status, she is exempted from house chores like cooking and fetching water, but when a man discloses his status he is not exempted from any of his bread earning jobs. (Female patient)

The society stigmatizes a man, even when he goes to the hospital; no one in the society cares about him, they consider him as a drug addict; and since he is neglected, he may even die alone. (Female patient)

... if you are unmarried then you [will] have a very hard time to get some food, because everyone around you has some more important things to do than cooking you some food, since you are getting a poor diet and the TB medications are very strong, then your life will be in jeopardy. (Male patient)

If you are a man, you can starve, for there will be no one to cook for you. (Male patient)

Stigma as a barrier to care-seeking

Cyclical nature of fear, health-seeking delays, continued transmission and poor health outcomes

Participants described how elements of TB-related stigma led to health-seeking delays, and the resulting continued transmission and poor health outcomes operated together in a vicious cycle to reinforce TB-related stigma in their community:

Yes, in my society patients are stigmatized and devalued to the extent of compromising their dignity; in such a situation when people start to experience TB symptoms they don't go to the health facility as they are afraid to be diagnosed with TB. (Male patient)

So people could not disclose their status to anyone except to their family members in fear of stigma, [and] since people were hiding their status, transmission rates were high. (Female household member)

Participants also described how TB-related stigma operated as a barrier to care by reducing the patient's strength of will to overcome all other types of barriers:

...stigma is not a barrier in accessing TB care except it makes the patient's spirit weaker when they are confronted with a barrier. (Male patient)

DISCUSSION

We report the current state of TB-related stigma in Dar es Salaam, Tanzania, an urban East African setting with a high TB burden and a substantial proportion of TB cases that go undetected every year. We found that TB-related stigma was prevalent in this setting, and that it was intertwined with other cultural norms, such as gender roles, relationships, and traditional beliefs about disease. Participants described the effects of TB-related stigma, both on their personal lives and on potential care-seeking behavior.

Our FGD participants reported significant differences in how TB-related stigma affects men and women. The conceptual framework presented in the Figure illustrates the interplay between stigma and gender. Gender affects the development of stigma through cultural beliefs about disease belonging more to the female realm. This is perhaps related to the tendency for women to be more likely to seek care for illness and to adhere to treatment, a phenomenon that has been observed in other TB studies.^{19,25} In addition, gender had very different effects between genders: for women, TB-related stigma resulted in difficulties in partner relationships and insults to their character from the community, whereas for men, cultural norms about TB and TB-related stigma threatened their survival. Other analyses of the interaction of TB and cultural norms about masculinity report similar findings.^{26,27} This link between stigma and cultural norms about masculinity, combined with the biological predisposition of men to become ill with TB, suggest that perhaps men are at risk of suffering more severely from TB-associated stigma.²⁰

Our findings have direct implications for TB control efforts in this and similar settings. TB programs and providers need to be sensitized to stigma and how differently it is perceived and experienced for men and women. In addition, interventions aimed at reducing stigma need to take into account the complex interrelation between stigma and other existing cultural constructs such as gender.²⁸ Attempts to address stigma will be more effective if they are designed with an understanding of the interaction between stigma and other cultural factors. The cyclical nature of TB-related stigma described in this study suggests that some aspects of stigma are self-reinforcing, and therefore that interventions aimed at interrupting this cycle could be effective at reducing TB-related stigma overall. Furthermore, efforts that are made to ensure that infection control measures taken by the household and community contacts of TB patients are done in a way that protects those at risk of acquiring the disease, without encouraging stigmatizing behaviors towards TB patients, could be beneficial. Partici-

pants' comments on the changes they have seen in TB-related stigma over their lifetimes highlight the malleability of TB-related stigma and suggest the potential for stigma reduction.

Our study has several potential limitations. Our findings are specific to the context in which the study was conducted and are not necessarily generalizable to all high TB burden settings. However, qualitative research is inherently designed to explore and characterize a particular phenomenon, and as such is usually specific to the setting in which it is conducted. Our sample size may have limited the findings of our study; however, even within our FGDs, we reached saturation on many topics related to stigma, so it is doubtful that more focus groups would greatly expand our findings. Our methodology of focus groups may have limited the information we received from the participants. FGDs are ideal for understanding cultural norms, but can be challenging for more sensitive, private topics. As stigma is both a cultural norm and a private and sensitive topic, it is possible that participants in this study reverted to more generic cultural truisms when discussing the topics at hand, instead of providing truly personal accounts.

In conclusion, TB-related stigma is prevalent in an urban East Africa setting with a high TB burden, it acts as a barrier to care seeking, and operates very differently for men and women. Interventions designed to address the challenges posed by stigma should be considered, and close attention should be paid to the interaction between gender and stigma.

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References

- 1 World Health Organization. Global tuberculosis report, 2016. WHO/HTM/TB/2016.13. Geneva, Switzerland: WHO, 2016.
- 2 World Health Organization. Addressing poverty in TB control. WHO/HTM/TB/2005.352. Geneva, Switzerland: WHO, 2005.
- 3 Godfrey-Faussett P, Kaunda H, Kamanga J, et al. Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. *Int J Tuberc Lung Dis* 2002; 6: 796–805.
- 4 Goffman E. Stigma: notes on the management of spoiled identity. Englewood Cliffs, NJ, USA: Prentice Hall, 1963.
- 5 Link B, Phelan J. Conceptualizing stigma. *Ann Rev Sociol* 2001; 27: 363–385.

- 6 World Health Organization. Gender, equity and human rights. Geneva, Switzerland: WHO, 2017.
- 7 Storla D G, Yimer S, Bjune G A. A systematic review of delay in the diagnosis and treatment of tuberculosis. *BMC Public Health* 2008; 14: 8–15.
- 8 Murray E J, Bond V A, Marais B J, et al. High levels of vulnerability and anticipated stigma reduce the impetus for tuberculosis diagnosis in Cape Town, South Africa. *Health Policy Plan* 2013; 28: 410–418.
- 9 World Health Organization Regional Office for the Eastern Mediterranean. Diagnostic and treatment delay in tuberculosis. EM/TDR/009/E/10.06/1000. Cairo, Egypt: WHO EMRO, 2006.
- 10 Hudelson P. Gender differentials in tuberculosis: the role of socio-economic and cultural factors. *Int J Tuberc Lung Dis* 1996; 7: 391–400.
- 11 Long N H, Johansson E, Lönnroth K, et al. Longer delays in tuberculosis diagnosis among women in Viet Nam. *Int J Tuberc Lung Dis* 1999; 3: 388–393.
- 12 Johansson E, Long N H, Diwan V K, et al. Gender and tuberculosis control: perspectives on health seeking behaviour among men and women in Vietnam. *Health Policy* 2000; 52: 33–51.
- 13 Ahsan G, Ahmed J, Singhasivanon P, et al. Gender difference in treatment seeking behaviors of tuberculosis cases in rural communities of Bangladesh. *Southeast Asian J Trop Med Public Health* 2004; 35: 126–135.
- 14 Eastwood S V, Hill P C. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa. *Int J Tuberc Lung Dis* 2004; 8: 70–75.
- 15 World Health Organization. Gender and tuberculosis. Geneva, Switzerland: WHO, 2003.
- 16 Yang W T, Gounder C R, Akande T, et al. Barriers and delays in tuberculosis diagnosis and treatment services: does gender matter? *Tuberc Res Treat* 2014; 2014: 461935.
- 17 Miller C R, Davis J L, Katamba A, et al. Sex disparities in tuberculosis suspect evaluation: a cross-sectional analysis in rural Uganda. *Int J Tuberc Lung Dis* 2013; 17: 480–485.
- 18 Borgdorff M W, Nagelkerke N J, Dye C, et al. Gender and tuberculosis: a comparison of prevalence surveys with notification data to explore sex differences in case detection. *Int J Tuberc Lung Dis* 2000; 4: 123–132.
- 19 Uplekar M W, Rangan S, Weiss M G, et al. Attention to gender issues in tuberculosis control. *Int J Tuberc Lung Dis* 2001; 5: 220–224.
- 20 Horton K C, MacPherson P, Houben R M, et al. Sex differences in tuberculosis burden and notifications in low- and middle-income countries: a systematic review and meta-analysis. *PLoS Med* 2016; 13: e1002119.
- 21 The International Federation of Anti-Leprosy Associations. Guidelines to reduce stigma. London, UK & Amsterdam, The Netherlands: The International Federation of Anti-Leprosy Associations, 2011.
- 22 Weiss M. Explanatory Model Interview Catalogue (EMIC): framework for comparative study of illness. *Transcult Psychiatry* 1997; 34: 235–263.
- 23 Richie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, eds. *Analyzing Qualitative Data*. Oxford, UK: Taylor & Francis, 1994: pp 173–194.
- 24 World Health Organization. Global tuberculosis report, 2014. WHO/HTM/TB/2014.08. Geneva, Switzerland: WHO, 2014.
- 25 Krishnan L, Akande T, Shankar A V, et al. Gender-related barriers and delays in accessing tuberculosis diagnostic and treatment services: a systematic review of qualitative studies. *Tuberc Res Treat* 2014; 2014: 215059.
- 26 Chikovore J, Hart G, Kumwenda M, et al. Control, struggle, and emergent masculinities: a qualitative study of men's care-seeking determinants for chronic cough and tuberculosis symptoms in Blantyre, Malawi. *BMC Public Health* 2014; 14: 1053.
- 27 Chikovore J, Hart G, Kumwenda M, et al. 'For a mere cough, men must just chew Conjex, gain strength, and continue working': the provider construction and tuberculosis care-seeking implications in Blantyre, Malawi. *Global Health Action* 2015; 8: 26292.
- 28 Pescosolido B A, Martin J K, Lang A, et al. Rethinking theoretical approaches to stigma: a Framework Integrating Normative Influences on Stigma (FINIS). *Soc Sci Med* 2008; 67: 431–440.

R É S U M É

CONTEXTE : Dar es Salaam, Tanzanie.

OBJECTIFS : Décrire la stigmatisation relative à la tuberculose (TB) et comprendre comment elle interagit avec le genre pour affecter l'accès aux soins.

SCHEMA : Huit discussions en groupe focal ont eu lieu suivies d'une analyse thématique du contenu avec 48 patients TB et les membres de leurs foyers.

RÉSULTATS : Les éléments principaux de la stigmatisation ont inclus la peur, l'isolement, la marginalisation, la perte de statut au sein de la communauté et la discrimination de la part des prestataires de soins. Les participants ont décrit le contexte culturel dans lequel la stigmatisation opère comme caractérisé par une ignorance générale en matière de santé, par des croyances culturelles vis-à-vis de la TB et par des croyances engendrées concernant la maladie en général. Les deux sexes ont décrit quelques effets similaires de la stigmatisation, comme les

difficultés relationnelles et plus spécifiquement celles de former de nouvelles relations, mais de nombreux effets de la stigmatisation ont varié en fonction du genre : les femmes ont décrit être en butte à des soupçons de promiscuité ou d'infidélité ainsi qu'à un rejet des partenaires, tandis que les hommes ont évoqué des problèmes de survie. La stigmatisation a constitué une entrave aux soins à travers un cercle vicieux de stigmatisation et de peur entraînant des délais dans la recherche de soins qui entraînent une poursuite de la transmission et des résultats médiocres en termes de santé qui à leur tour renforcent la stigmatisation.

CONCLUSION : La stigmatisation liée à la TB est prévalente dans ce contexte et opère différemment selon le sexe. Les interventions visant à augmenter la détection des cas doivent affronter la stigmatisation et son interaction avec le genre.

R E S U M E N

MARCO DE REFERENCIA: Dar es Salaam en Tanzania.
OBJETIVOS: Describir la estigmatización relacionada con la tuberculosis (TB) y comprender las diferencias de la interacción de los estigmas con el acceso a la atención de salud en función del sexo.

MÉTODO: Se realizaron ocho sesiones de debate en grupo y análisis de contenido temático con 48 pacientes aquejados de TB y miembros de sus hogares.

RESULTADOS: Los principales componentes de la estigmatización incluyeron el temor, el autoaislamiento, la exclusión por parte de los demás, la pérdida de posición en la comunidad y la discriminación por parte de los profesionales de salud. Los participantes afirmaron que el contexto cultural en el cual opera la estigmatización se caracteriza por una carencia total de conocimientos en materia de salud y creencias culturales con respecto a la TB y a las enfermedades en general. Las personas de ambos sexos coincidieron en algunos efectos de la estigmatización,

como la dificultad con las relaciones y en especial con el establecimiento de nuevas relaciones, pero muchos efectos fueron diferentes en función del sexo: las mujeres describieron problemas como las suposiciones con respecto a la promiscuidad y la infidelidad, además del rechazo por parte de las parejas; los hombres refirieron dificultades de supervivencia. La estigmatización constituyó un obstáculo a la atención de salud mediante un mecanismo circular de estigma y temor que origina retrasos en la búsqueda de atención y estos retrasos facilitan la transmisión continua y los desenlaces clínicos desfavorables que refuerzan a su vez la estigmatización.

CONCLUSIÓN: La estigmatización relacionada con la TB es frecuente en el entorno estudiado y opera de manera diferente en los hombres y las mujeres. Las intervenciones tendentes a aumentar la detección de casos deben abordar los estigmas y su interacción en función del sexo.